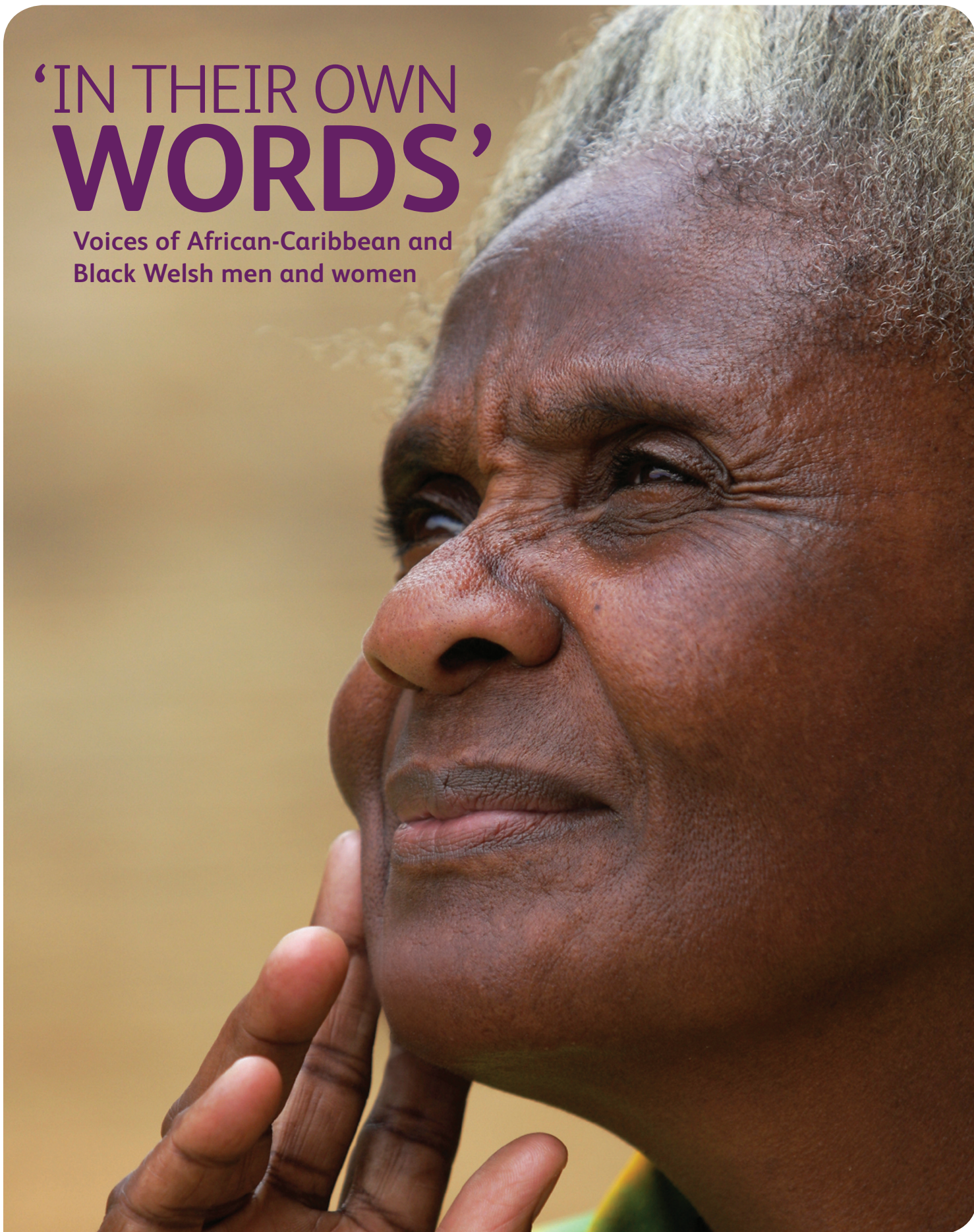


'IN THEIR OWN WORDS'

Voices of African-Caribbean and
Black Welsh men and women



A qualitative study to capture what dignity means to people aged 50 years and older, and their experiences and expectations of care and support



WERC

Wales Ethnicity Research Collaboration

Cydweithrediad Ymchwil Ethnigrwydd Cymru

‘IN THEIR OWN WORDS’

Voices of African-Caribbean and Black Welsh men and women

Roiyah Saltus & Liz Folkes (2012)

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Disclaimer

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Executive Summary

I would say dignity comes with no assumptions... you have no assumptions... you are seeing the person. People come with an assumption of somebody before they even treat them for anything or listen to them. You're presented as a body and then people come with their assumptions... Instead of saying 'assumption', you can put it as prejudice... we all come with prejudices that can hinder or stop people being treated in a way that they should be treated.

(019: Black Welsh woman, 55 yrs)

Background

Over the decades research in the area of dignity and ageing has grown in both the UK and internationally. Although the body of research evidence has helped significantly to refine the concept of dignity and to broaden the understanding of older people's care and support experiences, few studies have sought to:

- ▲ examine the concept of dignity and perceptions of dignified care as linked to personal identity, social identity and racialisation;
- ▲ develop an understanding of the possible impact this has on enhancing or damaging care encounters.

Aim of the study

This exploratory study is motivated by the fact that the number of older people in Wales, including those from Black and minority ethnic (BME) backgrounds, is set to steadily increase. The policies for older people in Wales, and the research evidence underpinning them, will have to reflect, and seek to provide effective services for, Wales' increasingly diverse older population. The aim of the study was to:

- ⤴ explore older people's experiences of care in order to bring conceptual and practical clarity to the concept of dignity (and associated indicators);
- ⤴ test methods of accessing the views and experiences of older people from BME communities.

Study objectives

The above aims were developed through the following study objectives:

- ⤴ conduct interviews and gather stories from a purposive sample of older adults living in Wales who self-identify as being linked (by ancestry, acculturation or association) to the following two broad (and overlapping) groupings: Black Welsh and African-Caribbean;
- ⤴ map and reflect on the role, value, and contribution made by community researchers and of community-based multi-practice organisations, providing recommendations and guidance on conducting research and engagement work in an urban, multicultural and cross-sector research context.

Methods

In order to meet the objectives of the study, a qualitative approach was taken; the overall approach was fundamentally interpretative. In regard to the collection of qualitative data that would allow us to explore the views, opinions, expectations and experiences of older people, semi-structured interviews were conducted with all participants. Drawing on relevant literatures, past knowledge and the experience of the research team, the interview schedule and aids were developed and piloted. In the final version, the following topics were explored: older people's understanding of dignity (what it was, what it 'looked and felt like'); how they acknowledged other people's self-worth; accounts of their experiences of care and perceptions of 'good' or high-quality care; the effect of needing extra care and support on

their lives and on their sense of self; exploring their social care needs; and awareness and uptake of sources of support, including that of social support.

Community researchers (CRs) were recruited to the study on a sessional basis to help with recruitment and outreach work, to help develop the data collecting tools, and to collect data. The final data collection tool used for the semi-structured interviews comprised 22 questions. The interviews lasted between 20 and 60 minutes, and were conducted between May 2011 and July 2011. In total, 22 interviews were conducted. All interviews took place at a time and location of the participant's choosing. Ethical approval to conduct this study was granted by the Ethics Committee of the Faculty of Health, Sport and Science, University of Glamorgan in January 2011.

Findings

The main findings that emerged from the data are related to the following overarching themes: (1) 'The virtue of age', (2) 'Mutual respect and reciprocity', (3) 'Social identity and racialisation' and (4) 'Expectations of care'. The first three themes are rooted in seeking to understand the meanings attached to the concept of dignity, how dignity is understood, important markers, acts and indicators of respectful encounters, and the significance of acknowledging, maintaining and preserving the dignity of, and the respect given to, older people. The last theme revealed the perceptions, experiences and expectations of care provision, and what care with dignity meant for the participants.

Dignity and the virtue of age

This first theme explored some of the key dimensions from which the concept of dignity is understood. The study revealed that many of the components of dignity identified in the research literature remain relevant, including dignity as stature, dignity as merit, and dignity as a basic human right. Moreover, the study also revealed the importance of dignity as linked to one's personal value system, cultural affinities and social networks. Key components included:

- ⤴ specific acts, attitudes and expectations;
- ⤴ the significance of the close proximity of families and communities, networks and geographic localities;
- ⤴ the intergenerational transmission and transformation of cultural mores and values linked to the respect given to older people.

It is important to note that such affinities were multilayered and interrelated.

Mutual respect and reciprocity

The second theme ‘Mutual respect and reciprocity’, is rooted in the mutual exchange of acknowledgment and the almost unanimous view that mutual respect and reciprocity are vital to the fostering of dignity and the acknowledging of a person’s self-worth. The study revealed that it is this interpersonal dimension of dignity that can also lead to the diminishing or corroding of one’s sense self-worth or self-dignity. There were several strands to this theme:

- ⤴ the belief that, when you treat other people with respect, you are, in turn, accorded respect by them;
- ⤴ the principle of viewing everyone as having an intrinsic value;
- ⤴ the belief held by some that, unless you possess respect for yourself, you cannot demand respect from others;
- ⤴ the lack of respect accorded to older people on a wider, societal level.

The key messages repeated most often by the participants were: the universal right to be respected, the significance of one’s self-worth, the links between self-respect and dignity in social encounters, and the impact of societal discrimination (*‘it’s this business of not seeing the other person’* (020: African-Caribbean woman, 76 yrs).

Social identity and racialisation

In exploring personal identity, it is evident that dignity has a structural dimension as well as an interpersonal dimension, both of which are constructed by the act of recognition. The study revealed that, as aspects of their personal identity, social markers such as ethnicity and cultural identity shaped the participants' understanding of the concept of dignity. The study shows that the process of racialisation impacts, to varying extents, on the participants' daily lives and on how they are recognised in dignity encounters such as the receiving of care. A key message is that attention to these elements is important, as is the need to develop an understanding of the possible impact such factors may have on enhancing or damaging a care encounter. Of equal importance is focus on the individual, and to glean from them what is important to the delivery of care with dignity. The findings discussed under this theme included:

- ⤴ the multifaceted nature of personal identities as viewed by the participants;
- ⤴ the array of fluid dynamic and interacting social identities which shape older people's experiences and expectations;
- ⤴ the links between the meaning of dignity and social identity;
- ⤴ dignity preservation strategies used by the participants.

Racialised differentials in health are increasingly being understood not simply as the result of 'cultural differences' but rather within the context of wider social, historical, economic and political factors (Anderson et al. 1989; Ville et al. 1994; Higginbottom 2006); this study revealed that factors such as social care access, acceptance, uptake and avoidance must likewise be understood as linked to these wider societal contexts. It is not solely about changing attitudes; it is about tackling wider structural barriers – barriers that are as much about age as they are about other social markers such as the race concept and minority ethnicity.

Expectations of care

'Expectations of care' focused on the participants' responses to the questions on their current or future care and support, their preferences regarding who is or will be delivering such care, and their views on what the delivery of care and support with dignity meant to them. The findings discussed under this theme included:

- ▲ the meanings of care
 - the informality attached to 'formal care'
 - care and caring as an important dimension of respect
 - the stark binary of low and high levels of support and care;
- care preferences
 - the expectation and desire for support from family
 - the fear of becoming a burden on one's family;
- help seeking behaviours
 - the knowledge, uptake or avoidance of care and social supports
 - 'doing it for themselves';
- perceptions and experiences of care
 - getting the care you want
 - care with respect
 - retaining independence.

The study revealed that not only was dignity important, but that the participants had strong views on what constituted quality care and of what they considered to be indicators of care with dignity. These included: acknowledgment of and attention to social markers linked to the personal and social identities of older people, as articulated by the person ('dignity with no assumptions'); professional competency of carers: active listening and communication; care that prolonged autonomy and independence; care delivered by people who were not only aware of individual preferences and cultural differences (or similarities as the case may be), but who were responsive and made appropriate adjustments. These were considered key enhancers and indicators of dignified care.

Key messages

- ⤴ The concept of dignity is of practical concern and relevance to the older people who took part in the study.
- ⤴ With a belief in the virtue of age came a level of expectation from some of the participants that they, too, will be respected and honoured as they got older.
- ⤴ There was an almost unanimous view that mutual respect and reciprocity are vital in the fostering of dignity and the acknowledging of a person's self worth. The most often used phrase was the importance of 'you treated people the way you expect to be treated'.
- ⤴ For some participants, the terms 'respect' and 'dignity' (and, conversely, 'disrespect' and 'indignity') could be used interchangeably; for others, one emerged from the other, with dignity described as the physical manifestation of the respect one has for themselves or receives from others.
- ⤴ How older people from racialised backgrounds who need extra care and support seek to preserve their dignity in later life may be related to how they have sustained themselves throughout the course of their lives.
- ⤴ The study revealed that for the participants, social markers such as ethnicity and cultural identity shaped their understanding of what dignity means and also had an impact on how they felt they would be treated in care encounters. A key message is that attention to these elements is important, as is the need to develop an understanding of the possible impact such factors may have on enhancing or damaging a care encounter.

- ⤴ There was anxiety around external sources of support and care and of not being treated with care and with dignity because of one's ethnic or cultural background.
- ⤴ The role of their families, and of religion and spirituality were considered to be of importance to some. The care provided by friends and family was understood by many of the participants as an indicator of respect shown by the carer to the person being cared for.
- ⤴ Care was most often conceptualised and discussed in an informal manner. The participants who were receiving care or support talked about people (friends, relatives, or social care workers) 'coming by' or 'helping out'.
- ⤴ The professional competencies needed in the delivery of care were considered to be more than just acknowledging important markers of the person's identity and being aware of ethnic or cultural differences. Rather, care providers must actively value these differences so that they meet any needs, preferences or requests arising from these.
- ⤴ Many felt that listening and communicating in the context of delivering care tailored to a person's specific needs is not difficult; rather it is something that we do in all areas of life. The delivery of high-quality professional care was down to intentionality and focus: the care provider's view of the worth and importance of older people.
- ⤴ The decision for some of the participants to 'soldier on' and to avoid asking for help, coupled with the lack of knowledge of the medium level supports offered were all key factors in shaping the participants' understanding, uptake or avoidance of social care provision.
- ⤴ There is need for further research on the relevance, importance and role of strategies, identity-linked resources and networks, and narratives of resilience and resistance used by older people from minoritised or racialised backgrounds in seeking to maintain and protect their sense of worth and dignity in care settings.

Structure of the Report

The report is divided into three parts.

Part One

Chapter 1: Provides a scoping review of relevant research literature. This chapter also includes a section spotlighting key policy drivers underpinning the study

Chapter 2: Provides an overview of the older adult population in Wales

Chapter 3: Describes the methodology underpinning the study

Part Two

Chapter 4: Describes the key themes emerging from the data

Part Three

Chapter 5: Provides a summary and discussion of the findings

Note on Key Terms

Older people: In this report, older people are adults aged 50 years and older, as defined by the *Wales National Strategy for Older People* (2008).

Ethnicity: A fluid, shifting and dialectical *process* through which collectives of people negotiate the social world. Over the course of time, groups identify themselves (or are identified by others) with reference to characteristics such as language and cultural practices and transmit this information down the generations. Sometimes a territorial claim is involved (Olumide 2002, p.31).

Black and minority ethnic (BME) groups: In the UK, the terms ‘minority ethnic’ or ‘ethnic minorities’ are most often used to refer to all minority groups of the population not indigenous to the UK that hold cultural traditions and values derived, at least in part, from countries of their or their ancestors’ origin. The term ‘black’ is often used not only to differentiate black minority groups from other minority ethnic groups, but rather to ensure that the continuing impact of the legacy of racism remains highlighted and is made problematic. ‘Black and minority ethnic’ (BME) people, populations and groups will be used in this report, with key minority ethnic groups taken as those included in the UK census classification system. It is axiomatic that BME populations are heterogeneous, with differences both within and between groups.

Racialised groups: The concept of race has been a pervasive force in the development of modern western society. Although found to have no biological basis, what we know as ‘race’ can be defined at its most basic level, according to Winant (2000), as a concept that signifies and symbolises socio-political conflicts and interests in reference to different types of human bodies (p.172). Accordingly, racialisation is the process by which people and groups of people are ranked on the basis of their presumed racial

differences and the attendant meanings of such differences in particular contexts. The process has long been contested and problematised.

Dignity: Our understanding of dignity is as defined by Tadd et al (2011): a fundamental right, subjectively experienced and rooted in one's perception of being treated and regarded as important and valuable in relation to others. Dignity is a multifaceted concept, which draws upon a person's sense of identity, autonomy and human rights and is shaped by a number of social markers such as ethnicity, gender or class (Matiti and Cotrel-Gibbons 2006). In this study, the concept (and operationalisation) of dignity is relational and contextual. Dignity arises and is maintained by the individual and their interaction with their social world.

Dignified care: The kind of care, in any setting, that supports and promotes, and does not undermine, a person's self-respect. Undignified care is characterised as that which renders individuals invisible, depersonalises and objectifies people, is abusive or humiliating, narrowly focused, and works to disempower the individual (Calnan et al. 2006).

1 Background to the Study

INTRODUCTION

Rooted in a review of research literature, this chapter provides an overview of the conceptual framework underpinning the study, covering (i) dignity and dignified care as linked to older adults, (ii) personal identity and racialisation, and (iii) participatory research. This chapter also includes a section spotlighting (iv) key policy drivers underpinning the study.



Dignity and dignified care

Drawing on a range of disciplines including human rights, clinical ethics, anthropology and health care, dignity has emerged in recent decades as a key factor in the delivery of good quality health and social care. Accordingly, a number of literature reviews and concept analyses of dignity and of care with dignity have been published in recent years (Fenton and Mitchell 2002; Jacelon et al. 2004; Coventry 2006; Anderberg et al. 2007; Gallagher et al. 2008) from which dignity can be understood to be a fundamental right, subjectively experienced and rooted in one's perception of being treated and regarded as important and valuable in relation to others. Nordenfelt's (2004) exploration of the varieties of dignity – universal dignity, dignity as linked to merit, dignity as linked to moral stature, and dignity of identity – is particularly useful in highlighting the key dimensions of dignity. Also important is the research of Anderberg et al. (2007) on attributes of preserving dignity, which include individualised care, control over one's life, respect, advocacy and sensitive listening.

A number of studies have explored the salience of dignity from the perspective of older people (Woolhead et al. 2004, 2006; Bayer et al. 2005; Levenson and Joule 2005) and in a range of care settings, including hospitals (Jacelon 2003; Bridges et al. 2009; Webster et al. 2009; Tadd et al. 2011), nursing homes (Franklin et al. 2006; Pleschburger 2007; Westin and Danielson 2007), and also from the perspective of health professionals (Arino-Blasco et al. 2005; Calnan et al. 2005). These findings are increasingly being used to inform practice within a range of health and social care settings and to develop domains and indicators of dignity that can be used in monitoring and assessing of care services (Faulkner 2006; Matiti and Trorey 2008; Picker Institute 2008; Clark 2010). Key elements of dignified care that emerge from the research include respectful communication; respecting privacy; promoting autonomy and a sense of control; addressing basic human needs such as pain relief, nutrition, elimination and personal hygiene needs in a respectful and sensitive manner; promoting inclusivity

and a sense of participation by providing adequate information to aid decision-making; promoting a sense of identity; focusing on the individual; and recognising human rights.

What also emerges from the literature is the fact that the delivery of care with dignity in health and social care settings is especially problematic for older people. A number of reasons for this have been identified, including the priority given to targets and budgets that can work to undermine dignified care, and the replacement of compassionate nursing care for more technically skilled practitioners (Webster and Bryan 2007). Others cite the power of ageism in society and ageist attitudes among staff (Bayer et al. 2005; Picker Institute 2008). Woolhead et al. (2004) noted that for many older people the loss of independence jeopardised their experience of dignity, autonomy and self-respect: a point more recently made by Tadd et al. (2011) who stated that encounters within formal support services settings have a tremendous potential to impact upon the individual's experience of dignity due, in no small part, to the unequal relationships between the various proponents in terms of knowledge, power, familiarity, wellbeing and dependence.

The research described above has helped significantly to refine the concept of dignity and to broaden the understanding of older people's experience of dignity in care. There remains a need, however, to explore how dignity is understood across a range of older population groups. The research evidence on ageing and dignity includes a smaller body of research on the experiences and views of older people from Black and Minority Ethnic (BME) backgrounds in the UK. This includes the work of Clegg (2003), who examined the concept of culturally sensitive care from the perspectives of older South Asian patients and their carers. Respect, understanding, spirituality and dignity were identified as central to this concept. Mold et al. (2005) review of research literature on minority ethnic elders in care homes

revealed the barriers to care provision, as well as the loss of independence experienced, and the need to recognise specific cultural needs.

Studies have also been conducted in England with older minority ethnic people and carers to understand their views on the quality of local health and social care provision, and the influence of old age, ethnicity, faith on their experiences of life-limiting illness, dementia and end of life care (Murray and Brown, 1998; Gunaratnam 2006; Manthorpe et al. 2009; Sin 2009). Cook (2010) explored the experiences of and barriers to accessing welfare citizenship services among older women living in Sheffield who had migrated in later life to Britain. In particular, the important constraints of discrimination and language differences were assessed.

In Wales, very little is known about the experiences of older people from black and minority ethnic (BME) backgrounds and their pathways through the care system (Burholt and Windle 2001). Thus, this study was driven by the need to explore how dignity is understood by minority ethnic older people and their experiences and expectations of receiving care, with a focus on social care.

Personal identity and racialisation

The study focussed on racialised population groups for several reasons. First, research has highlighted that older people and carers share common expectations, regardless of their ethnic and cultural background, about the quality of services and about the importance of dignified care (Cattan and Giuntoli 2010). However, as noted above, older people have individual expectations, aspirations and desires based on their life experiences, and cultural, religious and ethnic background (Bowes and Dar 2000); moreover, the notion of what constitutes 'care' may be interpreted differently between and within different ethnic groups (PRIAE 2008). What is evident is that how services are used and experienced by individuals from different ethnic groups is just as much a product of their own beliefs, needs and expectations, as it is a product of the attitudes and perceptions of service

providers (Patel 1999; Koffman and Higginson 2001; Bowes and Wilkinson 2003; Moriarty and Butt 2004). Deficiencies in local policy commitment, resource allocation and incomplete recognition of the culturally specific needs of some older people all function as barriers to service access and responsiveness amongst some minority ethnic groups (Manthorpe et al. 2009). Thus, older BME people face, to varying extents, barriers rooted in real and perceived social, cultural and ethnic differences, and a legacy of social exclusion, marginalisation and racism – factors that can lead to lower health and social outcomes and to lower levels of engagement with, and uptake of, health and social services.

Secondly, as Butt and O’Neil (2004) report, not only are the numbers and proportions of older BME people in the UK rising rapidly but the impact of ageing in terms of health and social care needs happens at a comparatively younger age in many minority communities. Evidence from the last UK Census showed the BME population of Wales had increased from 1.5 per cent (41,551) in 1991, to 2.1 per cent (61,600) in 2001. A continued increase was suggested by the 2007 mid-year population estimates, which showed the total percentage of people from BME backgrounds in Wales had risen to 2.9 per cent (86,300). Given the relatively young age structure of BME groups, the number of older BME groups in Wales is set to continue to rise. Developing a research evidence base for this segment of the population is set to become increasingly important.

Moreover, the ongoing social structural salience of race continues to be a pressing research concern (Miles 1989; Winant 2000). Over the decades, a key preoccupation with scholars has been to understand the many ways in which ideas about race are mapped onto particular groups or populations, the consequent forms of racism and contestation, and the impact this has on the health and wellbeing of people (Karlsen and Nazroo, 2002; Wray 2003). A key preoccupation of the study is exploring the possible impact this has on enhancing or damaging a care encounter.

In seeking to add to the existing research evidence on dignity and dignified care as understood and experienced by older people from racialised backgrounds, the theoretical model of dignity developed by Calnan and Tadd (2005) is important. Their model highlights the objective ('human dignity') and subjective (types of dignity: of moral stature, of merit and of personal identity) elements of dignity and thus provides a way in which to begin to explore the race concept as linked to one's personal identity, and how the imprinting of ideas of race and racialisation on one's personal identity shapes, and is shaped, in the context of social care encounters. Of utmost importance is recognising that people have identities and personal histories that make them who they are and that the ways in which others act towards them affects the way they see (Tadd et al. 2011).

Also important is Jacobson's work on dignity (2007, 2009). In her analysis, dignity is described as having two complementary but distinct forms: human dignity (as above) and social dignity. Within social dignity there is dignity-of-self and dignity-of-relation and it is the latter that, together with the work of Tadd et al. on dignity, is most useful. Dignity-of-relation refers to the ways in which respect and worth are conveyed through individual and collective behaviour as shaped by particular settings (private or public) and by a (modern, western) social order in which inequalities such as racism, sexism and ageism are deeply rooted. As such, the experience of living in a society structured by deeply rooted race inequality can shape an individual's identity as well as affect the way in which someone with that identity interacts with, and is perceived by, others. How older people from racialised backgrounds who need extra care and support seek to preserve their dignity in later life may be related to how they have sustained themselves throughout the course of their lives. As Winant (2000) in his analysis of critical race theory states:

The theme of race is situated where meaning meets social structure, where identity frames inequality (p.171).

Participatory research

...no research on race and ethnicity is either accidental or apolitical in its inception, practice or dissemination, in its inclusions and exclusions, its visibilities or its silences (Alexander p.146 in Black and Solomos 2004)

Race inequality is a pervasive fact of our world, and it is evident that socially ascribed differences such as 'race' and ethnicity are strongly implicated in how social inequalities are patterned in Wales. Funded by the Welsh Government, this study was conducted under the auspices of the Wales Ethnicity Research Collaboration (WERC), a research network comprising a growing number of academics, community development activists and researchers, who are committed to carrying out and supporting high quality health and social science research (www.werconline.org.uk/). The majority of qualitative research undertaken by the WERC is participatory and community-based; we are a research group dedicated to working with, and on behalf of, population groups that have historically been discriminated against, with an interest in tackling issues of importance to them. Community-based research is rooted in finding ways of working collaboratively with groups of people affiliated by cultural or ethnic affinity, as well as by geographic proximity or special interest, to address issues of importance to them. For population groups that face marginalisation and discrimination, a community-based (or community-engaged) research approach may be more sensitive to their circumstances, needs and perspectives than more traditional research approaches.

Policy drivers

The Welsh government has frequently expressed its commitment to creating policies and programmes that reflect the needs of an ageing society and, over the last decade, there has been a social policy shift away from high-level need to concerns with prevention and facilitating independence. More recently, there has been an increasing focus on broader

notions of independence including the maintenance of dignity, quality of life and wellbeing in later life. It is important to reflect, albeit in brief, on the Welsh policy context in which the drive for dignity has emerged and gained strength in recent years. What follows is a snapshot of some of the policy drivers in place in Wales.

- ⤴ In 2003, dignity was highlighted as a key principle in the *Strategy for Older People in Wales* (2003), underpinned by the United Nations Principles for Older People.
- ⤴ The concept of dignity is a crosscutting theme in the *National Service Framework for Older People in Wales* (2006), and is an underpinning principle of its Person Centred Care Standard. Dignity and respect are also included in national standards linked to care homes and domiciliary care.
- ⤴ The Strategy for Social Services in Wales, *Fulfilled Lives Supportive Communities* (2007), places a focus on the needs of the user, on social inclusion and the rights of individuals, and on promoting good outcomes.
- ⤴ In 2007, the ‘Dignity and Respect in Care’ programme for Wales was launched, followed by a series of regional events and the dissemination of a workbook and other resources on dignity to all NHS Trusts in Wales (Tadd et al. 2011).
- ⤴ The *Welsh Assembly Government’s Single Equality Scheme* (2009–2012) includes an action to promote equality and diversity in health and social care research and development in Wales.
- ⤴ The *Old People’s Wellbeing Monitor for Wales* (2009) stresses the need to develop sub-analyses of many of their indicators, including those linked to dignity.
- ⤴ Dignity is an issue that, by law, the Older People’s Commissioner for Wales must address and, in her first Review, *Dignified Care? The experiences of older people in hospital in Wales* (2011), evidence was gathered on older adults’ experiences, both good and bad, when they are hospital in-patients.



A Demographic Overview of the Older Adult

POPULATION IN WALES

Table 1 – Older people in selected Welsh local authorities

AGE	FEMALE	MALE	TOTAL	% OF POPULATION LIVING IN AREAS
WALES				
50-59	194375	185385	379760	12.63159
60-69	186600	178957	365557	12.15917
70-79	128299	111031	239330	7.960604
80+	98746	57244	155990	5.188546
SWANSEA				
50-59	8567	7853	16420	13.13852
60-69	13812	12408	26220	11.27737
70-79	10083	8549	18632	8.013729
80+	7634	4709	12343	5.308794
THE VALE OF GLAMORGAN				
50-59	8567	7853	16420	13.13852
60-69	7800	7287	15087	12.07192
70-79	5161	4526	9687	7.751088
80+	4086	2408	6494	5.196198
CARDIFF				
50-59	17874	17317	35191	10.31831
60-69	14136	13643	27779	8.145044
70-79	10641	8482	19123	5.60703
80+	8879	5008	13887	4.071789
NEWPORT				
50-59	8443	8324	16767	11.86574
60-69	7758	7293	15051	10.65135
70-79	5534	4635	10169	7.196439
80+	4385	2352	6737	4.767667

The number of older people in the UK is rising. Since 1983, the number of people aged over 65 years has increased by 18 per cent while the numbers aged over 85 have doubled. By 2033, it is estimated that one in five people will be over 65 years with the greatest increase being in the oldest old, (85 years and above)(Wise 2010). Wales has the highest proportion of older people with 22 per cent of the population aged over 65 compared with 19 per cent in the UK as a whole. The most recent data on the configuration of the Welsh population comes from the 2010 mid-year estimates of the population (Statistical Directorate 2010). In Wales, nearly two fifths of the population are aged over 50 (39.6 per cent). The highest proportion of people aged over 50 are located within the 50-59 age bracket (12.6 per cent) while those aged over 85 represent the smallest proportion of older age groups in Wales (5.2 per cent). As can be seen from Table 1 above, the proportion of older age groups living in Wales is very similar to the proportion of older age groups living in each of the four local authority areas examined, particularly in Swansea and the Vale of Glamorgan. There was a slightly lower proportion of older people across all older age groups living in both Cardiff and Newport compared to the Wales average.

Snapshot of BME population groups in Wales

The 2001 census data is the most comprehensive source of data on specific BME population groups in terms of the age composition and geographical distribution of these groups across Wales. The 2009 mid-year population estimates are disaggregated by ethnic group; however, the age groups are split into three broad categories (0-15; working age; pension age) and therefore do not provide a picture of the spatial distribution of different groups of BME older people across Wales (Statistical Directorate, 2009).

However, the mid-year population estimates provide data on BME population groups as a whole. Between 2001 and 2009, the percentage of people in Wales from minority ethnic groups increased from 2.1 per cent (61,000) to 4.1 per cent (123,700). In 2009, the largest minority ethnic

group in Wales was Asian or Asian British. This group made up 1.8 per cent of Wales' population (52,700) and the majority were from Indian and Pakistani backgrounds. The next largest minority ethnic group comprised those from a mixed ethnic group background (29,800), followed by 'Chinese or other ethnic group' (28,600). Those who were 'black or black British' were the smallest of the BME groups (18,600) with the majority coming from Black African backgrounds. Only four local authorities had larger minority ethnic populations than the Wales average: Cardiff (11.1 per cent), Newport (6.3 per cent), the Vale of Glamorgan (4.9 per cent) and Swansea (4.7 per cent) (Statistical Directorate, 2011).

African-Caribbean and Black Welsh population groups

Black Caribbean people and their descendants have lived in Britain for over 300 years, although there was a significant increase in the number of people from the Caribbean between the 1940s and 1970s. This can be demonstrated by a Home Office report in 1963, which summarised New Commonwealth Migration by the census returns, between 1891 and 1951, of people born in the Caribbean (Walvin 1984):

Year	Number of people recorded
1891	8,689
1901	8,680
1911	9,189
1921	9,054
1931	8,585 (there was no census in 1941)
1951	15,301
1961	171,800

In Wales during the mid- twentieth century, people came from several of the Caribbean islands, with the majority of people coming from the islands of St Kitts, Nevis, Barbados and Jamaica. Today, those who can trace their heritage directly, or in part, to the Caribbean live throughout Wales, with the

largest numbers living in Cardiff. In terms of population figures, based on the 2001 census, the Caribbean group has a population size of 0.44 per cent (1,343) in Cardiff. However, the number of people of Caribbean descent is most likely greater, as many now fall in the 'mixed ethnic group' UK census categories.

The term 'Black Welsh' is as much about ethnicity and nationality, and a sense of belonging to and being part of Wales, as it is about the race concept. For since the 1800s, people from all over the world settled in Cardiff, other areas of south-east Wales and beyond. The waves of migration have left a strong imprint; the mixed ethnicity groups are the fastest-growing groups in the last census, with Wales having the highest number of mixed ethnicities in the UK. A significant number of this group comprise those with links to the Caribbean and Africa. Coupled with the more recent influx of people from these parts of the world, there is now, in Wales, a growing number of people who identify themselves as being Black Welsh. From the findings, it is clear that there are clear distinctions to be made between the two target groups, as well as clear linkages.

The 2001 census of the population shows that there were 3,300 people from black minority ethnic backgrounds resident in Cardiff who were aged 50 and over. Of these, approximately four fifths are aged 50-69 (see Table 2 below).

Table 2 Older BME population in Cardiff

Age group	Number	%
50-59	1421	43.1
60-69	1205	36.5
70-79	516	15.6
80+	158	4.8
Total over 50	3300	100

Drawing on the 2001 Census, the table below highlights older people of different age groups from Caribbean and African ethnic backgrounds in Cardiff as a proportion of the total number of BME people of these age

groups resident in Cardiff. Just over one fifth (21.1 per cent) of older BME people aged 70-79 identify as Black or Black British and Black Caribbean. Just under one fifth (19 per cent) of older people aged over 80 are from Black British–Black African backgrounds.

Table 3 Proportion of older adults from Caribbean and African backgrounds in Cardiff

	White and Black Caribbean	White and Black African	Black or Black British and Black Caribbean	Black or Black British and Black African
Aged 50-59	6.0	3.7	7.7	8.0
Aged 60-69	4.6	4.5	14.9	7.6
Aged 70-79	10.7	3.5	21.1	13.8
Aged 80+	13.3	0	14	19.0

Finally, the number of females and males of older age groups from these backgrounds is outlined in Table 4 below.

Table 4 Age and gender profile of older adults from Caribbean and African backgrounds living in Cardiff

		White and Black Caribbean	White and Black African	Black or Black British and Black Caribbean	Black or Black British and Black African
Aged 50-59	Total	85	53	110	115
	Male	49	31	59	54
	Female	36	22	51	61
Aged 60-69	Total	56	54	179	92
	Male	28	30	102	52
	Female	28	24	77	40
Aged 70-79	Total	55	18	109	71
	Male	28	11	70	43
	Female	27	7	39	28
Aged 80+	Total	21	0	22	30
	Male	10	0	16	16
	Female	11	0	6	14

2001 Census of the Population

3 Methodology

INTRODUCTION

This chapter provides information on the aim and objectives of the study and its design, the recruitment of the research participants, and the data collection methods. This chapter also details the key components of the data analysis.



Study Aims & Objectives

This exploratory study is motivated by the fact that the number of older people in Wales, including those from BME backgrounds, is set to steadily increase. Policies for older people in Wales, and the research evidence underpinning them, will have to reflect, and seek to provide effective services for, Wales' increasingly diverse older population. We wanted to find out how dignity and dignified care is viewed by African-Caribbean and Black Welsh people aged 50 years and over; we also wanted to capture their experiences and expectations of care.

Study Aims:

- ▲ To explore older people's experiences of care in order to bring conceptual and practical clarity to the concept of dignity (and associated indicators); To test methods of accessing the views and experiences of older people from BME communities.

Study Objectives:

1. To conduct interviews and gather stories from a purposive sample of older adults living in Wales;
2. to map and reflect on the role, value and contribution made by community researchers and of community-based multi-practice organisations.

This report will present the activities and findings linked to the first aim and objective.

Design and methods

For this study a qualitative approach was taken. Qualitative research works to can capture the immediacy and complexity of real lives, uncovering the differences and similarities between individuals, and how they interpret the world and make sense of their place within it. Such an enquiry generates

detailed, situated, contextualized data that can answer how‘ and why‘ questions and reveal human agency. Thus, the overall approach was fundamentally interpretative and so met the study objectives to explore the experiences and expectations of older people. As well as being exploratory, this study is also a pilot study, with the aim of testing the data collection instruments and assessing the success of the sampling.

As the aim was to collect stories (as well as to collect other qualitative data), a narrative approach was adopted, with the key question asked as follows: ‘can you tell me of your experience of asking for or receiving “good” or “not so good” social care?’ A variant of Franks’ (1997, 2008) dialogical narrative analysis was chosen to be used, in which a research participant’s story of experience forms the basis for a conversation between storyteller and researcher, with the story being developed through iterative cycles of revision and validation. In this way, the interactive search for meaning and understanding of the experiences of BME elders that takes place during interview/storytelling is considered in the ensuing formal analytic cycle, before being returned once again to the storyteller for reflexive interactions (Mahoney 2007).

In regard to the collection of other qualitative data that would allow us to explore the views, opinions, expectations and experiences of older adults, semi-structured interviews were conducted with all participants to allow for a in depth exploration of key issues and topics, whilst allowing the researcher to retain a degree of control via the standardisation of the interview process (Denscombe 2003). Drawing on relevant literatures, past knowledge and the experience of the research team, the interview schedule and aids were developed and piloted. In the final version, the following topics were explored: what dignity ‘looked and felt like’; ways of acknowledging other people’s self-worth; accounts of experiences of care and perceptions of ‘good’ or high-quality care; the affect of needing extra care and support; awareness and uptake of sources of support, including that of social support.

Ethical approval

Ethical approval to conduct this study was granted by the Ethics Committee of the Faculty of Health, Sport and Science, University of Glamorgan in January 2011. The importance of informed consent was discussed during the recruitment process and written consent was obtained at interview. Assurances were given that the participants' confidentiality and anonymity would be protected. This was explained so that they had a clear understanding that no identifying information would be held about them or associated with their responses. All recordings of the interviews were destroyed on completion of the research study. All documentation was kept in locked cupboards according to research governance regulations. Participants were informed of their right to withdraw and that they could withdraw their consent and terminate their involvement in the project at any time without giving reason. No participants did withdraw.

The participants

Following ethics approval, participants were recruited via the extensive established social networks and contacts of the community researchers (CRs) who were part of the research team. The CRs were able to gain access to potential participants by using a combination of purposive (Silverman 2001) and snowball sampling (Bowling 2002). Using purposive sampling (i.e. those sampled on the basis of a range of experiences or circumstances linked to the study aim and sampling criteria) potential participants were identified and invited to take part in the study and, thereafter, snowball sampling allowed for participants to nominate one other potential participant. This continued until the sample size was met. There are known limitations to snowballing, which include possible recruitment of people of similar backgrounds. However, this strategy is often used when conducting research with marginalised groups (Atkinson and Flint, 2001).

Moreover, we are mindful of the danger that the ethnic minority categories used in the UK censuses that we adapted in the study (Black Caribbean and Black British/Welsh) would not necessarily correlate with the terms used the participants to describe themselves. Therefore, the recruitment criterion included people who considered themselves to be connected to the targeted group(s) by reason of upbringing, birth or acculturation.

Study sites

All interviews took place at a time and location of the participants' choosing. The majority of the interviews were conducted in the participants' home, or the homes of the community researchers. One interview held in a local community centre and one interview held in a local church hall.

Organisation of data collection

As an exploratory pilot study, one important aspect of the design was to develop and test not only the study design, but the interview schedule. Community researchers (CRs) were recruited to the study on a sessional basis to help with recruitment and outreach work, to help develop the data collecting tools, and to collect data. The CRs were responsible for piloting the interview schedule, interviewing and validating the findings; organising discussion groups and public meetings; and assisting in the purposive and progressive sampling schedule. Upon completion of training linked specifically to the study, the CRs gathered the interview data, along with other members of the research team.

During the recruiting process, participants were asked to take part in a one- or two-part interview process based on whether they had a 'story of experience' to share. Thus, it was intended that a two-part interview would take place over two visits with the research participants. However, we were not able to recruit participants to take part in narrative interviews as originally designed. This was discussed at length by the research team and will shape future, larger studies. All the participants took part in one

interview; the data collection tool used comprised 22 questions. The interviews were conducted using one set of six small portraits of older people and elders (the portraits are dispersed throughout this report), and one set of eight cards with short phrases drawn from the research literature on dignity, as listed in the side bar.



Feeling valued
Being understood
Being respectful
Being treated as a individual
Valuing my religion
Valuing my culture

Once a short demographic questionnaire had been completed, the face-to-face interviews were audio recorded with the participants' permission. The demographic questionnaire, completed by the interviewer prior to the interview, covered gender, ethnic background, marital status, country of birth and

length of residence, general health, uptake of social services and supports, employment history and caring responsibilities. The interviews lasted between 20 and 60 minutes, and were conducted between May 2011 and July 2011. The participants were not paid to take part in the study. As an

acknowledgement of the time they gave to the study and as a token of our appreciation, all participants were given a £10 gift voucher.

Data analysis

The approach to the data analysis was fundamentally inductive and interpretative. Drawing on the methods of thematic data analysis (Silverman 2009), typed notes and verbatim interviews were analysed, with the aim of identifying overarching themes that would provide an understanding of the meaning of dignity held by the participants and their experiences and expectations of receiving formal and informal support and care. Analysis of the data commenced as soon as data were collected.

In the initial reading of transcripts, notes regarding salient points were made. The aim was to identify and assign a label (or code) to key explanatory ideas or concepts emerging from the data. Two members of the research team analysed a sample of the interviews separately and discussed the index system/coding framework (i.e. the list of nodes/codes used to categorise the data and their meanings). Once agreement was reached regarding the index list, the rest of the interviews were analysed, with a sample analysed by two members of the team. The use of independent coders to evaluate and verify the coding and the categorisation of the data facilitated interrater reliability (Tinsley and Weiss 2000). Concepts that were closely linked in meaning were brought together as categories from which key themes emerged.

Emergent, as well as known, categories (i.e. those linked to the research literature, the knowledge and experiences of the researchers that formed the basis of the piloted interview schedule) were explored iteratively and, as part of the process, coded passages were constantly compared with other coded passages to ensure that the coding was consistent and to explore whether there was a need for new codes to capture themes emerging from the data. This continued until no new categories were identified. Original transcripts

were constantly rechecked to ensure that themes and thematic patterns accurately reflected the original data. The qualitative analysis software package QSR Nvivo, version 8 was used to assist in the coding, and in the subsequent thematic grouping process.

Note on steps taken to ensure rigour

The following steps were undertaken to strengthen the rigour of the study:

- ⤴ The conceptual and theoretical framework (Chapter One) sets out, to some extent, the key standpoints of the researchers in regard to the subject matter of this study.
- ⤴ The interview schedule was designed based on an extensive review of the research literature, with a focus on validated dignity indicators and known under researched dimensions of dignity
- ⤴ The interview schedule was piloted. The members of team listened to the recordings, and as a team, questions were modified to make them more appropriate, and in some instances, less leading.
- ⤴ To ensure the accuracy of the transcription, a sample of the interviews were transcribed by two transcribers and checked by a member of the research team for accuracy and consistency.
- ⤴ Two members of the research team analysed the data. This allowed for verification of the coding and the categorisation of the data, which facilitated interrater reliability.
- ⤴ The participants' views of the initial interpretations of the data were sought a short time after the end of data collection to explore the believability of the findings. Four participants provided participant validation.

- ⤴ There was triangulation of data sources (via the meetings and discussion groups with the members of the target groups before and after the data collection phase), and of sites (individuals linked to one local organisation, and individuals recruited that had no such links).
- ⤴ Extracts from the interviews have been included, in part, as one way in which to audit the development of the themes.
- ⤴ The eight categories or dimensions that Meleis (1996) proposed as essential for evaluating methodological rigour in research and scholarship: contextuality, relevance, communication styles, the awareness of identity and power differentials, disclosure, reciprocation, empowerment and time shaped, were integrated as key points of reflection throughout the course of the study (as detailed in the accompanying report).

Study limitations

- ⤴ The interview aids proved useful to some, but not to the majority of the participants. For some participants the images presented to them were not helpful and did not provide a full enough range of human experience or examples of dignity. The phrases presented to the participants were drawn from research evidence and, although useful, a concern could be that they introduced bias and shaped the participant's views. Potential bias was offset by the aids being presented part-way into the interview after the participants had formulated and shared, in some detail, their views of dignity and respect unaided.
- ⤴ The use of the term 'dignity' in the interview question of a study that is seeking to clarify the concept of dignity could also be considered problematic. The use of the term 'respect' was used as a way to explore the salience of the concept of dignity; the term 'dignity' was used but no definition of the term was provided, with the onus being to invite the participant to share their views on the term, to offer

alternative terms and views, and to arrive at a version of dignity that they were comfortable with.

- ✧ We are clear that the findings are not designed to be transferable across the wider minority ethnic population. The research design meant that the study did not include older people living outside the large Welsh cities in areas where the BME population is less than 2 per cent, such as in north and mid-Wales. However, the aim was to test our interview schedule and research approach. In future studies, we will replicate our tested research design and approach across Wales, and we will aim to target a wider range of BME groups.
- ✧ Although confined to urban locations in one regional area of Wales (SE Wales), and to those not living in residential care, the targeted groups are diverse in terms of age, mobility, membership of clubs and groups, and length of time living in Wales.

4 The Findings

INTRODUCTION

This chapter details the study findings. The main findings are related to the following overarching themes: (1) 'The virtue of age' , (2) 'Mutual respect and reciprocity' (3) 'Social identity and racialisation' and (4) 'Expectations of care' . The chapter will start by profiling the participants.



The participants

Table 5 Participants' Country of Birth

Participants' Country of birth (N=21)		
Country/Region	Number of participants	
Caribbean/West Indies	13	The concept of saturation and standard estimates of samples for qualitative studies (above 15 and
Wales	7	
England	1	

below 50, according to Guest 2006) guided the sample number for this pilot study; the aim was to recruit 12–15 participants. However, due to interest in the study, 21 participants in total were recruited to the study. The majority of the study participants were first and second generation African-Caribbean (West Indian) men and women. The remaining participants were part of the long-established third and fourth generation population in Cardiff of mixed ethnicity who identified themselves as Black Welsh.

Table 6 Number of years resident in the UK

Number of years	Number of participants	
Fewer than 10	1	The tables above show participants' country of birth and the length of time resident in Wales.
10–19	0	
20–29	1	
30–39	0	Most participants were born in the Caribbean/West Indies.
40–49	4	
50 and over	7	
From birth	8	

One fifth of the sample was born in Wales. Of those who immigrated to the UK, half had done so over 50 years ago, while four have been in the UK between 40 and 49 years. Most of the participants immigrated in the late 1950s and early 1960s. Just one participant had immigrated as recently as one year ago. The socio-demographic profile of participants is displayed in Tables 6 and 7 below. Three quarters of the sample are female and the majority of participants were aged 50–59.

Table 7 Age and Gender of the participants

Age	Gender (N= 21)		
	Male	Female	
50–59	4	5	Half the participants rated their health as 'good' with one participant rating their health as 'very good'. A quarter rated their health
60–69	1	2	
70–79	0	6	
80–89	0	3	
Total aged 50 and over	5	16	

as either 'bad' or 'very bad'. Nine of the participants were retired, with just under half the participants either in full-time employment or self-employed. Three participants lived in sheltered accommodation and, of those who were divorced, separated or widowed, the majority lived alone.

Table 8 Participants' socio-demographic characteristics (N=21)

Marital Status	
Married	1
Unmarried partner	1
Separated	3
Divorced	8
Widowed	5
Single	3
Health Status	
Very good	2
Good	10
Fair	4
Bad	3
Very bad	2
Employment Status	
Employed f/t	7
Self-employed	4
Unemployed	0
Retired	9
Never worked	1

Utilisation and supports

The number of participants who used social services and who were in receipt of some of the core benefits available to older adults is presented in Table 9 below. In terms of the key payment supports received by most of the older people in this sample, payments were towards the cold weather (N=9), winter fuel (N=7) and council tax (N=7). In relation to pension provision, five participants indicated that they were in receipt of the state pension, one indicated that they received the state pension in addition to a private pension, and one participant indicated that they were in receipt of pension credit, while five participants were in receipt of the pensioners' Christmas bonus. In terms of the kind of benefits that are received by these participants, two received Disability Living Allowance (DLA), three received housing benefit (one of these also received income support in addition to housing benefit) and one person received incapacity benefit.

Just a few participants used services related to home care provision, such as the personal/domestic care home service, while a few have adaptations to their homes or communication equipment to enable independence and extra security. Support in relation to housing needs is utilised by a few of the participants. In general, it appears that a small number of the same participants utilised the aforementioned services and supports.

Table 9 Participants' Social service utilisation and support

Service utilisation or support	Social services (N=20)
Yes	6
No	14
	Social benefit recipients (N=19)
Yes	11
No	8

The Themes

The findings are presented in narrative form. Extracts from the interview data have been included as part of the findings; in some cases the text has been edited to enhance understanding. The aim is that, by including extracts, the reader is given greater insight into the expressed views and experiences (the 'voices') of the participants from which the findings are rooted. In this report, we have used the cultural or ethnic identifiers given by the participants (i.e., African-Caribbean, Black Welsh, Black British and West Indian). The participants' extracts include their unique identifiers. The individual identifiers include ethnic and cultural background, gender and age as provided by the participant (e.g. 021: Black Welsh woman, aged 84).

'The virtue of age'

This study was designed to illuminate older people's understanding of the concept of dignity. Several points can be made in regard to this first theme. First, all the older people who participated in this study expressed the view that the acknowledgement of an individual's worth, and the receiving of care that enhanced and did not corrode an older person's dignity, were important and necessary, and that the aims and the focus of the study were important and timely. This 71 year old African-Caribbean woman's response, for instance, when asked if there was a need to explore the views of older Caribbean and Black Welsh people was:

Older people from the Caribbean need to be asked. We have played a valuable role in the development of British society and our views and experiences should be sought; we need to be acknowledged, respected and accepted (004).



THE VIRTUE OF AGE

DIGNITY
VALUE
MERIT
TE

DIGNITY AS LINKED TO ONE'S PERSONAL VALUE SYSTEM
THE SITUATIONAL CONTEXT IN WHICH DIGNITY IS OPERATIONALISED
DIGNITY AS STATURE | THE SALIENCE OF DIGNITY | DIGNITY AS MERIT

Another participant stated:

I think it is good that the study is being made about people like me because people like me they tend to be very quiet... they just go along with the system and they try to manage the best way they can and seem satisfied with their lot! And it is good that there is an enquiry to find out if there is anything that could be done for people like me.

(008: West Indian woman, aged 68)

Secondly, as well as the view that the experience, knowledge and wisdom that older people possess are qualities or virtues that should be valued, described in the research literature as 'dignity as stature' (Nordenfelt 2004), many of the participants expressed the view that being an older person is a revered status and by virtue of this alone, a person should command respect. This notion of the virtue of age felt to be important to the participants can be understood as what Nordenfelt (2004) describes as 'dignity as merit'. As one participant explained, '*... it doesn't matter who it is. It could be the worst person ever, you still treat them with respect*'. (002: African-Caribbean woman, aged 73) When asked about what they thought their parents meant when they told them as children to 'treat your elders with respect', reminiscences included:

Older people were valuable people. Older people had experience of life that I should hereby listen to. Older people were people to copy in terms of behaviour. Older people were people who would have advice that would be good for you. Older people were your other parents!

(020: African-Caribbean woman, aged 76)

Well, as young kids growing up, our parents would say show respect; even though we are far away, we are still to look up to our elders as our role models. We have to show them respect as an elderly people.

(014: Black British man, aged 54)

Being respectful is a big thing in Caribbean culture; it's part of life being respectful and to have people respect you for who you are as an individual and for what you've done and what you continue to do. Some people would argue about respect working both ways, but I think you

know for the older person to be shown respect for your age is a good thing.

(009: African-Caribbean woman, aged 56)

Thirdly, for most of the participants, the perception of the virtue of age was a deeply engrained part of their personal value system. As one participant put it, respect for older people was something taught at *'a mother's breast'* (020: African-Caribbean woman, 76 yrs). This became apparent in the exploration of the operationalising of dignity – in the participants' responses to questions on their views on what the acknowledgment of an older person's worth 'looks like'. The responses from both the sample groups were fairly consistent and there was considerable agreement about what was regarded as respectful behaviour and dignity-enhancing attitudes and actions. Specific acts committed with deference included addressing older people by their surnames and not by their first names, opening doors and giving up your seat to an older person, always greeting older people first, sitting quietly and not talking back ('not giving back chat') or being rude, loud or too familiar, and, lastly, offering support, help and assistance to older people without being asked or as one participant explained, *'helping them in their need'* (010: West Indian woman, aged 73). Some of these specific acts are evidenced in the following extracts:

Speak nice to people, be polite... We used to call people Mr and Mrs; I know some families call each other Auntie and Uncle. We weren't brought up like that, so it was about treating people good and nice and listening to them if they spoke to you and not being cheeky.

(012: Black Welsh woman, aged 53)

You would never pass an elderly person on a road without acknowledging them and sometimes as children, if you are doing anything silly or you are playing rough and you see an elderly person passing, you stopped.

(003: African Caribbean woman, 53 yrs)

In seeking to explore the roots of this theme further, a fourth sub-theme emerged: the close proximity of families and communities in small geographic localities or as part of close-knit social networks – in Wales or in the Caribbean – was also an important factor that shaped the participants' understanding of the concept of dignity. As a child growing up in such communities, it was understood that one's behaviour was liable to come under scrutiny by any adult, not just your immediate family. Any act of disrespect would quickly become widely known and would reflect badly on your family as a whole. As recounted by one participant: *'Because you are known in your community... if you should dare to disrespect an elder, they would complain'* (004: West Indian woman, aged 71). Moreover, being respectful towards others was a sign that you respected your parents and their (and the family's) position in the community:

Regardless whether they were a family member or not, you took your cue from the parent that somehow this person could be offered respect through, because the respect you were giving was to the parents so they would be offered respect through your parents.

(003: African-Caribbean female, aged 53)

Also, with a belief in the virtue of age came a level of expectation from some of the participants that they, too, will be respected and honoured as they got older. For some this was a source of comfort and enhanced their sense of self and their worth, as expressed by one of the participants:

I gave all the respect to my elders; now that I'm elderly I expect some respect... Within my family I know that I'm valued because my son tells me 'I love you Mum' and he kisses me so that in itself makes me feel valued and I think feeling valued comes primarily from my family.

(010: West Indian woman, aged 73)

Linked to this was the perception held by some of the participants that, within the family, extended family, and close family friends' social network context, this attitude towards older people was passed on and, although to some this was weakening, it remained an important cultural or community norm. As one participant (018: West Indian man, aged 65) explained: *'a lot*

of respect has gone down the drain...but fortunately for us it is still in our community'. For a few another participants it was important, as one participant put it (O20: African-Caribbean woman, aged 76), *'to show respect to younger people so that they will learn how respect is shared'* as one way in which to pass on to the next generation the importance of respecting and acknowledging the virtue of age and the importance of older people. It is perhaps axiomatic, but the data also revealed the situational nature of dignity. For many of the participants, but not all, the family setting and one's social networks were sites that enhanced self-worth. External public settings, unfamiliar surroundings and being in the company of people less known to them were considered to pose, to varying extents, possible threats to their sense of worth.

A final point to make is that, in contrast to the communities of their childhood and youth and the cultural mores around respect and dignity of older people that for many of the participants remained important and alive, when asked if they felt that older people were still accorded more or less respect, most participants expressed the view that older people were not respected in today's society. Several of the respondents who identified themselves as Black Welsh attributed this to attitudinal differences between themselves and the younger generation, suggesting that young people were no longer raised to respect their elders. Many of the first and second generation African-Caribbean respondents explained the change by exploring the cultural differences between the Caribbean and the UK. The following extracts may provide a deeper understanding of this point:

Interviewer: Now do you feel as you get older you are treated with more or less respect?

Participant: Um, that's a hard one. I think in the culture that I live and have been in since I was a teenager I tend to say no in many areas, because if I compare or think about respect in the Caribbean, for example in [name of a Caribbean island], and compare it with here in the UK, I'd have to say no [people are treated with less respect], But if I was in, for example [name of a Caribbean island], I'd be more ready to

say yes [older people are treated with more respect].... There has to be a difference between a younger person and an older person. I think if you're brought up with that idea of respect in older people it stays with you for life. Whereas over here, for example, if you saw older people and people are not taught to hear and say this kind of thing, I think that the need for respect is not quite the same.

(009: African-Caribbean woman, aged 56)

Yeah, because people, especially in this country, people have no respect for one another. They just, you know, call you by your name or even the little children, they don't call you Miss so and so or Auntie so; they call you to your name no matter how small they are. They call you by your first name and I think that is very disrespectful.

(006: West Indian woman, aged 80)

Well because you have got a situation where the younger generation are coming through and if their parents haven't taught them respect... nowadays respect isn't high on the priority list is it? You see it all the time with the youth... where they won't step aside when you are walking down the street to let you though. They can see you coming but they won't make a path for you. They are quite prepared to let you go on the road.

(017: Black Welsh man, aged 55)

Participant: I help to care for my mother so I was leading her into the [name of a local centre] and these two young people pushed past me and I said, 'hold on you could see us coming' and they said, 'we are in a hurry' and I said, 'you are not in that much of a hurry'. So I said, 'step back and let us finish going in' and the one started talking a load of rubbish... I would not have thought of doing that.

Interviewer: Yes.

Participant: I would have stepped back... I would have waited for the older person to go in... I would not have argued with them.

Interviewer: ... Because you would have thought instantly you were in the wrong?

Participant: Well, not just that. It is just that, that wasn't code.

Interviewer: Yes.

Participant: You know, I just think that there is a different code now.

(007: Black Welsh woman, aged 61)

‘Mutual respect and reciprocity’

The second key theme to emerge from the data was that of mutual respect and reciprocity as vital to the fostering of dignity and the acknowledging of a person’s self-worth. The expectation of reciprocity as cited by the participants can be conceptualised as interpersonal dignity: ‘dignity that is achieved in the eyes of others, as perceived by the individual who is the object of the other’s attention’ (Jacelon 2001: 256).

There are several strands to this theme. First, the belief that when you treat other people with respect you are, in return, accorded respect by them in their dealings with you featured heavily in the responses of all the participants to questions linked to how their sense of self-worth was fostered and maintained in their daily lives. The great majority of participants made the case in terms rooted in the practice of doing as you would be done by, and the expectation that others would do the same. This particular aspect of reciprocity came across most strongly in this theme, and was most commonly put in phrases such as ‘*you treat the person as you would like to be treated*’ (002: African-Caribbean woman, age 73), or ‘*... show people respect... respect will always eventually come back to you*’ (014: Black British man, aged 52).

Other participants cited the principle of viewing everyone as having an intrinsic value with the universal right to be respected and, as one participant reflected, ‘*... each individual needs to feel that they are accepted as a human being*’ (004: West Indian woman, aged 71).



MUTUAL RESPECT AND RECIPROCITY



MUTUAL RESPECT AND THE EXPECTATION OF RECIPROCITY | SELF RESPECT
DIGNITY AS AN ATTRIBUTE OF RESPECT | THE CORROSION OF DIGNITY

For other participants, the belief system upon which their interaction with the world was based was grounded in their religious faith. As one participant (008: a West Indian woman, aged 68) explained:

Well, I maintain I am a Christian so I maintain my integrity in God and I believe that as a Christian I should live a life that would give honour to God and people should see something in me that is different from the norm. The way I carry myself, the way I deal with other people, should reflect who I am. It is my belief [that] if you give respect you get respect because I believe respect is a two-way thing and if we respect other human beings they will respect us as well in return.

Second, coupled with this onus on mutual respect was the belief held by some of the participants that, unless you possessed respect for yourself, you could not expect to demand respect from others, or as one participant put it, ‘... *you have to show respect to get respect*’ (005: West Indian woman, aged 78). Another participant explained, ‘*I believe that what is most important is my respect for myself and, without that, others can’t respect you. No one is going to respect you if you don’t respect yourself and vice versa*’ (017: Black Welsh man, aged 55).

In making a similar point, another participant made the case that a lack, or low sense of self-respect should not mean that a person is treated as less worthy, as she stated:

I view respect as something you must accord yourself and if you don’t it is difficult to expect to be respected by someone else. Not that someone shouldn’t treat you with respect regardless, but if you show and act in a way that shows you respect yourself, that you regard yourself as valuable, as important and all the rest of it... then in a way it forces others to respond to you in a respectful way... at the same time just because I don’t see myself as worthy doesn’t mean you have to treat me as not worthy.’

(020: African-Caribbean woman, 76 yrs)

A third sub-theme links self-respect with dignity. In this context dignity was

taken to be an attribute of respect. For some participants, the terms 'respect' and 'dignity' (and, conversely, 'disrespect' and 'indignity') could be used interchangeably, as one participant explained, *'Well they're interactive aren't they? How do you break the two down? Dignity becomes the respect that you have for yourself. So therefore I see it as basically the same'* (017: Black Welsh man, aged 55). For others, one emerged from the other, with dignity described as the physical manifestation of the respect one has for themselves or receives from others:

Well, the two things are closely linked: dignity and respect. I think dignity might be a way that respect shows itself because if a person carries oneself with dignity it is because they respect themselves. If you are treated with dignity by others it is partly because they recognise the respect in which you hold yourself and the expectation from them that you will treat them with respect.

(020: African-Caribbean woman, aged 76)

Others saw dignity as distinct from, although closely linked to, a person's self-respect or pride. Several respondents provided examples of situations where an affront to their pride had the potential to impact upon their sense of dignity. One key area was concern about needing help with toileting and personal care, with the potential loss of dignity linked to the loss of self-respect:

One thing that is always in my mind is toileting. Now to me that's the biggest loss of dignity that you can experience. So if that ever had to happen to me, they would have to treat me in a way that was ok... so I am still left with my self-respect and they don't make me feel like 'Oh I feel so ashamed'.

(012: Black Welsh woman, aged 53)

In regard to the notion of reciprocity, it was clear that dignity and self-respect were enhanced or compromised by social interaction, as explained by one participant, *'If you got respect... you maintain your dignity and once you start losing respect, then your dignity falls.'* (018: West Indian man,

aged 65). Moreover, like respect, dignity was felt to be a quality that one needed to nurture in order for it to be reciprocated by others, as expressed by one participant, *'Dignity's a two-way thing: if you don't feel dignified, other people aren't going to see you as being dignified. You need dignity yourself before you can get dignity reflected by other people'* (010: West Indian woman, aged 73). Another participant made a similar point, stating that:

For me, if you have self-respect then, to a degree, you expect others to respond to you in a certain way or if they don't, you are more likely to recognise that they are not treating you in a dignified way.

(021: Black Welsh Woman, aged 84)

A fourth sub-theme is the link between a lack of respect and the corrosion of dignity on a wider, societal level. The diminishing of regard for people as they aged and a growing tendency for people to value older people less and less were cited. Many of the older participants (those 68 years and older) recounted experiences when not only were they not listened to, they simply weren't asked and assumptions were made. Terms of address are very important to many older people. Many respondents cited it as an example of the way they had been expected to behave towards older adults and several expressed their own dislike of being called by their first name. Other participants recounted care (social and health related) encounters when they were made to feel invisible and commented from their own experience of how the views of older people were not generally valued and frequently went unsought and unheard and the impact this has.

It is worth noting that not all the participants recounted such stories; several of the participants were unable to recall an occasion where they felt had been treated with disrespect or in a way that diminished their sense of worth. The following extracts may provide a deeper insight into some of the views and experiences expressed by the participants:

Participant: *It is this business of not seeing the other person. As you get older and the other person sees you in their mind's eye, views you as unimportant to them, no longer able to give them what they want or need, then you disappear from their perspective so they don't see you and they don't hear you.*

Interviewer: *Okay and, with that, come associated feelings of...?*

Participant: *For me?*

Interviewer: *Yes*

Participant: *Annoyance!*

(020: African-Caribbean woman, aged 76)

I think that on the whole I am treated with respect and dignity and that's because I expect it and so on the whole I am.

(003: African-Caribbean woman, aged 53)

They don't ask. My aunt was in the hospital. She was a very proper woman and she said to the nurse, 'I didn't tell you that you could call me [gives her first name] you know; I heard the nurses going on. So it goes back to what I said originally. It is not treating the person as someone who is worth your time and attention. So you have made all kinds of assumptions beforehand about how you are going to treat them; that is taking something from the other person I think.

(007: Black Welsh woman, aged 61)

Interviewer: *So how does that make you feel when somebody disrespects you, you know?*

Participant: *Well, it is upsetting in a way because you are not used to it...*

(015: West Indian woman, aged 76)

‘Social identity and racialisation’

The way in which a person’s personal identity shapes and is shaped by daily interactions is a theme that was evident throughout the data. So far, this has been discussed in relation to the personal value system underpinning the participants’ understanding of the concept of dignity as linked to the virtue of age. As explored above, for many of the participants, explanations of the meaning of dignity were framed in both their understanding of expected actions, behaviours and attitudes they grew up with and those they were now faced with in Wales, with those participants with established roots in Wales also noting intergenerational attitudinal shifts. Like all other ethnic groups, these explanations are rooted, in part and to varying extents, in the personal belief systems and the social, cultural and ethnic backgrounds of the participants.

The data underpinning this theme covers a number of areas. First, in regard to how participants chose to identify themselves, it is worth noting that how the African-Caribbean sample identified themselves did not vary to any noticeable extent. The majority chose to identify themselves as ‘West Indian’ or ‘African-Caribbean’, with some spotlighting the importance of their ancestral links to Africa or their colonial links and identification as British subjects and others making use of terms such as ‘Black African’ or ‘Black’ to spotlight the social and political dimension of the positioning in people in society according to skin colour. This seemingly consistent manner of self-identification does not lessen the important differences between the participants in terms of the islands of their (or their parents’) birth, social class, employment histories, or length of residence in Wales. Rather it highlights the fact that, for the majority of older West Indian people, there remain strong, stable links with the islands of their birth; it is these links to the islands of their birth that remain a key frame of reference.

SOCIAL IDENTITY AND RACIALISATION



PERSONAL IDENTITY AS MULTIFACETED | DIGNITY AND SOCIAL IDENTITY
SOCIAL IDENTITY, RECIPROCITY AND SOCIAL STRUCTURE
DIGNITY AS LINKED TO RACIALISED SOCIAL IDENTITIES
DIGNITY PRESERVATION STRATEGIES

The participants who identified with the umbrella identifier of 'Black Welsh' also gave detailed explanations of their personal identities as linked to their ancestral links. As one participant stated succinctly, *'My cultural background? I am Black Welsh. My ethnic origins are Caribbean; the two merge in terms of the way I live'*. (007, Black Welsh woman, aged 61)

Another participant explored this further stating:

I think because I was born and raised in Wales... I feel distinctly Welsh, but because, when we were growing up, there was a strong Caribbean community I know of my Caribbean heritage you know. It's not something that's distant, it's part of me as well. So I think I'm uniquely African-Caribbean and Welsh.

(019: Black Welsh woman, aged 55)

For others, mostly the participants with long-established roots in Wales, their personal identity and their cultural affinity to Wales was very much stronger, as one participant remarked simply when asked to describe herself, *'Welsh – Black Welsh'*. (021: Black Welsh woman, aged 84) Another participant's response to the same question provided insight into the wider societal overtones in play in the development of one's personal identity, as well as the fact that identities are not fixed. Her response:

Because of the way things have progressed over the years, I'm always unsure as to what politically correct things I should be describing myself as. I always just say I'm mixed race and my grandfather was African, but I would say my culture is Welsh through and through.

(011: Black Welsh woman, aged 53)

These aspects of their personal identity can also be understood as social markers imprinted with ideas of race and racialisation that, in turn, shape and are shaped by the everyday interactions of the participants. As one participant explained:

I identify being Black or mixed race and Welsh. As far as I am concerned, ethnic minority seems to be a label for anyone who is not white, or from

the British Isles. I am about three or four generations Welsh and, as a Black Welsh person whose family have lived here for generations, we have contributed to this country and helped to build Wales to what it is...I do resent being called an ethnic minority – I am proud to be Black and Welsh and want to be recognised as that – as a patriot of this country and a part of its fabric.

(012, Black Welsh woman, aged 53)

Secondly, the data revealed that the process of racialisation impacts, to varying extents, on the participants' daily interactions and on how they were 'recognised' in dignity encounters such as the receiving of care. As noted at the beginning of this report, in the context of this study, the process by which groups of people are defined and positioned unequally in society based on apparent differences in skin colour, is most commonly referred to as racialisation. A consequence of this racialisation is racism. For one participant this was an important element of why showing respect to one's elders and others within her community, and of fostering a strong sense of self-respect, was so important. As she explained:

I grew up in an environment where everything was segregated according to race – separate schools, churches, separate places to sit in theatres, separate places to sit in restaurants... So the notion of respect and of making your way was something that we were taught both directly and indirectly. You knew you would have to do certain things and that there were barriers that either your generation or the next generation somehow were going to have to change. So the notion of treating people - especially people of your own ethnicity - was very important because we had to be together to protect each other, to help each other, to support each other and so forth. So that was the constant erosion that we all grew up with around that time and we all became aware of ourselves and, I think, having to deal with that as I grew older meant that certain things were very, very important to me and nobody was going to erode that. So respect was the thing because if I didn't have a sense of my self-respect nobody was going to. I guess that underlies a lot of the things I think and do now."

(020: African-Caribbean woman, aged 76)

For others, it was important to acknowledge the basic human right of a person to be treated with dignity, irrespective of their ethnic or cultural background. As one participant explained,

'For me to be respected or valued means that I expect to be treated as a person; it doesn't matter about my colour. I think each individual has the right and is entitled to common courtesy.' (008: West Indian woman, aged 68)

Thirdly, the concept of race and of structural inequality based on 'race' was a factor seen by some of the participants as a factor that could very well work to diminish a person's sense of worth. When explaining what dignity meant, one participant explained the importance of dignity as being linked to recognition of a person without assumptions or the imprinting of prejudice or the presumption of unequal difference:

I would say dignity comes with no assumptions... you have no assumptions... you are seeing the person. People come with an assumption of somebody before they even treat them for anything or listen to them. You're presented as a body and then people come with their assumptions... Instead of saying 'assumption', you can put it as prejudice... we all come with prejudices that can hinder or stop people being treated in a way that they should be treated. So I would say dignity is about somebody else treating you with no assumptions.

(019: Black Welsh woman, aged 55)

For some, this meant that they could face even less chance of being respected and of receiving high-quality care. The few participants who had watched a series of programmes during the time of the interviews, and who expressed their concerns about possible bad quality care, noted that, based on their ethnic background, they stood even less of a chance of receiving good quality care. As one participant went on to state, *'I feel that, if they do that to a white person, what will they do to a black person like me? It's frightening.'* (001: Black West Indian woman, aged 80)

Linked to this sub-theme was the view that the race concept had to be understood as part of a range of factors that include these social markers but can also include other factors such as the professional competency of health and social care practitioners, which needed to be addressed when seeking to provide care with dignity. Of note is the power differential in play in any social interaction and how this shapes how people and differences between people (real and perceived) are (re)produced. In recounting an experience of having to complain about the manner in which a relative was being treated and the perceived lack of respect and acknowledgement given to the cultural norms in place in her home life, one participant went on to explain:

I think they got caught up into stereotypes and you could hear it. It was when we were talking to them, they had one stereotype and they seemed quite put off by our challenges... and also there was a bit of 'we know best'. I just think they just got themselves in all manner of tizzies and their values were leaking all over the place, which was really difficult because they wouldn't accept challenges and got very defensive... You know, we were tempted to say, well this is racism and some elements of it were but it wasn't fully and we were clear about that, but I don't think other families would have been.

(003: African-Caribbean woman, aged 53)

Lastly, a sub-theme that emerged from the data were the strategies used by some of the older people who took part in this study to protect and preserve their own sense of self-worth in the face of societal prejudice and discrimination. The strategies cited included the avoidance of places where one's sense of dignity could be compromised:

To keep my dignity, I wouldn't want to go in a home... I always like to be by myself, like now, living on my own. The only thing I'm afraid of is illness; that's the only thing... I am afraid of but I'm not afraid. I feel better living by myself.

(001: Black West Indian woman, aged 80)

Also, proclamations of having never been in a social care (or other care) encounters that diminished their sense of worth made by quite a few of the participants, including one who stated, *“I can honestly say no-one disrespects me. If they do, I don’t hear them anyway!”* (002: African-Caribbean woman, aged 73). The introspective life reviewing of their achievements and their links to family and friends that some of the participants shared can also be understood as strategies used by some of the older people who took part in this study to protect and preserve their own sense of self worth in the face of societal discrimination

“I have reminders around me, visual reminders of good that I know I have done whether it is in my children, or physical things that I have acquired. I was saying to a friend of mine just yesterday I figure I have done my share... let fight others fight the battles for their generation.”

(020: African-Caribbean woman, aged 76)

Other strategies included more direct interventions to address potential acts of disrespect, as evidenced in the following extract by a participant who was explaining how she insisted on being recognised as she felt she should be:

There’s an expectation on my part and also I put that into if it’s not happening... Somebody came to see me once and this person was like 18 and she said... ‘Hello you must be (female first name)) and I said, ‘ I must be Mrs (surname)... I thought to myself ‘why are you calling me (states female first name)), do I know you?’”

(003: African- Caribbean woman, aged 53)

The refusal to communicate with formal carers who chose to speak to family members and not to them, refusing to engage with what was being requested or ‘telling them (the carers) off’ or making your voice heard were other interventions. One participant cited one such incident:

My Auntie had Parkinson’s. She used to mumble and unless you were at her level you couldn’t hear what she was saying you know. We were at the hospital one day and I had said her arm was going darker and he looked and he said ‘well the other hand is quite dark’ and she said, with all the dignity she could muster, ‘I happen to be a colored person!’ And he said ‘oh, oh I see yes’. He hadn’t realized that she was colored, but

you know... it was the way she said it. It took quite a big effort I think to throw her voice."

(007: Black Welsh Woman, aged 61)

‘Expectations of care’

The themes explored so far have been linked to how the participants understood the concept of dignity. The last theme is based on the participants’ responses to the questions on their current or future care and support, their preferences regarding who is or will be delivering such care, and their views on what the delivery of care with dignity meant to them. The sub-themes explored in this section were also drawn from the participants’ responses to questions on their experiences and expectations of care.

The meaning of care

The data revealed a range of perspectives on the meaning of care in general and how, in particular, the participants conceptualised and gave meaning to the social care they currently received or expected to need to receive in the future. First, people did not readily acknowledge social care provision they were in receipt of. Only a small number of people interviewed were living in sheltered accommodation and so were obviously being provided with social support and benefits. They chose to take part in the semi-structured interview. The remaining participants indicated in preliminary discussions that they were not in receipt of social support, other than some social benefits. Once the study was under way, however, it quickly became evident that some of the participants recruited to the study on the understanding that they were not receiving social care provision were indeed in receipt of such services.

EXPECTATIONS OF CARE



BEHAVIOURS
MEANING
EXPERIENCES

THE MEANING OF CARE | CARE PREFERENCES | HELP SEEKING BEHAVIOURS
PERCEPTIONS AND EXPERIENCES OF CARE | EXPECTATIONS OF CARE

Secondly, the data revealed that care being provided as an outcome of a social service assessment was more often spoken of in incidental terms – *‘I had this girl’* (006: West Indian woman, aged 80) – and thus was not always conceptualised or articulated as formal ‘care’. It is worth noting that some of the participants had social care provision that had been arranged via social service agents whose work involved community-based engagement work with small local groups and organisations. Such engagement work meant that, often, services were arranged and monitored by these outreach staff in familiar settings. Such arrangements worked to foster still further an understanding of some of the participants of the informal nature of the rather formal processes of social care provision.

Thirdly, the evidence from this study reinforces the findings from previous research with older people that respect is perceived as being an important aspect of dignified care. What emerged from the views of our respondents is that this relationship can be inverted: care is an important dimension of respect and dignity. The care provided by friends and family was understood by many of the participants as an indicator of the respect shown by the carer to the person being cared for, as explained by one participant, *‘Well, that’s just it; treat them with respect in every way. Caring for them if they’re ill; seeing to their needs’* (022: Black Welsh man, aged 62). Another participant, when comparing the Caribbean and Britain, commented, *‘here in Britain I don’t think the elderly are loved but, in the Caribbean, to respect your elders you love them’* (010: West Indian woman, aged 73). For another participant, showing you care was an important element of recognising a person’s worth:

Well, basically, just looking after them and saying ‘hello’, checking on them if they happen to need any help. I mean often enough I go and knock on old people’s houses just to say hello just to cheer them up.

(013: Black British man, aged 53)

Fourthly, many participants indicated that they understood what extra care, including social supports, meant, citing such things as help with their daily activities in regard to practical support, personal care, help around the house, shopping, home adaptations, befriending, and the provision of day-care activities. The data revealed, however, a stark binary between this low level support and high level support such as residential care homes. Although many of the participants expressed their desire to remain at home and to be independent as long as possible, the data reveals that there seems to be limited knowledge of how to achieve this and limited knowledge or use of the low and medium level social supports available.

It is of worth to note that this was not the case of all the participants. Some participants were knowledgeable of, and were currently (or in the past) in receipt of, a range of formal social supports and services. These participants listed the supports presented to them at the start of the interview and discussed their experiences of using them throughout the interview (to be discussed further below). For those with previous experience of social care supports, the knowledge of such services did not necessarily mean that they intended to explore those options for themselves, as the discussion below details.

Care preferences

For many of the participants, the avenue to care and social support was binary: either their family or friends, or residential care, with the former option being the decided preference for the majority of – but not all – the participants. For instance, the response from one participant to the question of who you would want to provide you with the extra support or care was *‘You don’t want to be a burden to your children, but it would be your children that you would look to first rather than outside agencies’* (017: Black Welsh man, aged 55). The expectation of family members providing the care was also clear, as evidenced by this participant’s response to the same question:

Yes, family is so important. You got to have family, even if it is your own children helping you when you get older. They come, they clean and cook and do the business for you. That is what families are supposed to do. If you haven't got that, then you are on your own and you will struggle a bit.

(013: Black British man, aged 52)

For some others, caring for older relatives was still part of what you were expected to do and such care should be extended to those in need for as long as possible, as one participant stated, *'the longer it can be stretched out as a family, the better'* (018: West Indian man, 65 yrs). Even though care provided by family members was espoused as the ideal, several respondents expressed reservations that, although they had grown up with the expectation that they were to support their family elders, they acknowledged that family structures had changed. Some expressed the view that they did not want their own children to be under a similar obligation, practically or emotionally, as cited by one participant, *'I don't want my children to have to do that to feel obligated... I was brought up where you had an obligation to elder people and I don't think that is fair'* (007: Black Welsh woman, aged 61).

Another participant revealed her view on the gendered dynamic of care:

It is hard to say because at the moment both of my children, although grown, haven't got children of their own and I think it just depends really on their family network. Like 50 years ago most women didn't work; you know the men used to work and the women used to look after the children but it's not the case today is it. You've got children and you've still got to go to work so no I can't really answer that. If they didn't have children I would probably expect more support from them.

(011: Black Welsh woman, aged 53)

Help seeking behaviours

When asked how extra support and care was going to be arranged, this was the response of one participant, *'My family probably will want to but, see my attitude is if, as long as I've got my wits about me and I'm mobile then*

I'm fine and I'll ask for that outside help from the Social Services' (012: Black Welsh woman, aged 53). The response of another participant was, *'I would actually go and speak to the housing association or council and ask them to get someone to come in and check me over once a week or twice a week'* (013: Black British man, aged 52). For another participant, the family was not considered the preferred option – rather the most appropriate person or agency as she (or her family) would determine when the time arrived:

Interviewer: ...*Who could you see providing that extra care and support?*

Participant: *The people most appropriate to provide it. I don't have the kind of view of 'no, my family will do it'... I think it's going to be about who is going to be the most appropriate person to do it.*

Interviewer: *And would you want it to be your family?*

Participant: *NO, because my family members may not be the most appropriate people to do it.*

(003: African-Caribbean woman, aged 53)

However, such responses, which suggest that help would be sought from external agencies, were expressed by only a few of the participants. It was more common for respondents to express a dogged determination to carry on without external intervention. What was also revealed is that it was not the case that social care support provision would not necessarily be welcomed or taken up if it became absolutely necessary; rather it would not be actively sought. Moreover, knowledge of such services did not necessarily mean that participants intended to explore those options for them. Having expressed the high opinion she had of the health and social services in the care of her late ex-husband, this participant went on to state:

Participant: *I hope that I can carry on and do for myself as best I can without having to ask anybody else you know.*

Interviewer: *So you won't look for social support? You would not like social services?*

Participant: *No. To be truthful some of them, not all of them, but some of them can be too, too pushy. I think people take various people's liberty before they need to. I mean like they are saying they are doing a job. All right, it is good to know that there is somebody there when you need them, but some of them take away people's liberty too soon.*

(002: African-Caribbean woman, aged 73)

The participants cited possible reasons for the reticence or avoidance of social support. One respondent drew attention to difficulties in accessing services, particularly for those with limited language skills or experience of new technologies:

A lot of the ways you find out information is through using PCs, etc. Not everybody has a PC especially in terms of the elders and I am noticing more and more services being provided where they expect you to respond by using technology.'

(022: Black Welsh man, aged 62)

Another participant reflected on the reluctance of older people to feel inclined to ask for support beyond that of their family and social networks:

I would say again about the different generations of, um, my parents and especially their parents would never think about asking for help and even older people I support now. If you try to help them, like some benefits they're entitled to, they don't think they should have those benefits because they're, say it was for attendance allowance because maybe twice a week they're feeling fine but for five times a week they're not so well and they could do with the extra help but they don't see it like that; they just think that they shouldn't be entitled to anything really.

(011: Black Welsh woman, aged 53)

Thus, the role of the family in providing care, the ways in which 'formal' care was conceptualised and came to be understood by some as 'informal' and incidental, the importance for some of the participants to 'soldier on' and to avoid asking for help, coupled with the lack of knowledge, for some, of the medium level supports offered are all key factors in shaping the participants' understanding, uptake or avoidance of social care provision. As noted above, this was not the case for all the participants; some indicated in their responses that they would actively seek, and indeed would prefer formal social care provision.

Perceptions and experiences of care

In the interviews, questions were asked that were linked directly to the participants' perceptions and experiences of care. The responses varied, although as research as shown (Bayer et al 2005), it is often easier to recall negative experiences of care. A few participants recounted their or family members' experiences of receiving good quality care. One participant gave this response when asked about the care a family member received:

Well [name of a relative] had a carer coming to wash him. I used to do the cooking and feed him myself.... They gave us the equipment we needed. We had everything, I won't lie about them; we had everything.

(002: African – Caribbean woman, aged 73)

What also emerged from the data was the perception that the care would not be respectful, as stated by one participant, *'there are some harsh people, they haven't got time you know; it's hard to do things properly; they just cut and go... it is as if the elderly are taking too much of their time'* (001: Black West Indian woman, aged 80). Some of the participants perceived, and had witnessed, care that did not acknowledge or enhance a person's sense of worth:

Yes, so it's all one mad rush. There was no dignity or respect there and really it was all as if he was just a piece of meat:[it was] 'cup of tea, bye, we're gone'. There was no 'how are you today, tonight Mr [name]' or 'I'll sit you in the chair now and have a little chat'. No, it was nothing and I think that's all about money again.

(011: Black Welsh woman, aged 53)

Another participant explained that *'if I needed care I would hope the carer would be... respectful. I don't want any cheeky madam coming here and pushing me around in my home'* (010: West Indian woman, aged 73). The explanation of another participant was:

For example, again going from what I have heard and read, you know you could have people coming in and actually telling you, you should be doing this or doing that! Talking down to you, you know. I am not saying they all do it but there has been quite a few cases where it has and that again is going to undermine you and your own self-respect. You are going to get to a point whereby you may then decide not to take the help that is out there. You might decide, oh, I would rather struggle along as long as I can or do without even, you know, just to have your own self-respect in yourself, you know”.

(017: Black Welsh man, aged 55)

Linked to this was the experience of some that social care was not always what they wanted or had agreed to. Participants spoke of the trouble they had getting people to provide personal care according to an agreed schedule, getting carers to ‘move with them’, and securing practical support that was appropriate. This was one participant’s recollection:

They don’t do the things they’re supposed to do because, if you’re paying somebody to do something, you expect them to do it because I like my things done properly: I don’t like people giving me a six for a nine.

(006: West Indian woman, aged 80)

Another participant cited possible consequences of not receiving the care you want, but not being able to voice your preference and concerns:

...They suffer in silence, they don’t actually, not so much that, they don’t complain because they don’t feel that they’re going to get the service they want, so they withdraw and say they don’t want a service at all. My mother used to say when she was going into a Home, ‘oh, my daughter will sort that’... they don’t want them [the carer] and they either withdraw or they make it so difficult because they can’t get their point across. They can’t get their point across in terms of the care that they want because they know why they don’t want somebody to do that, but because it’s a cultural thing they’d rather not say.

(019: Black Welsh woman, aged 55)

It is of worth to note that for some participants, language was seen as a barrier to communication. For some of the participants, the accents, patios and Creole used commonly in many of the Caribbean islands had been retained and as they get older, the effort and inclination to communicate in received English pronunciation becomes problematic and burdensome, not least when in distress or not well.

The participants' views on residential homes varied. For a few of the older people who had been born in the Caribbean and noticeably more of those who had been born and raised in Wales, the prospect of at some point living in a residential home was welcomed. One participant's response was that her preference *'would be to live in a home. Yes, that would be my preference. And family could come and visit me'* (020: African- Caribbean woman, 76 yrs). Another participant cited her reason for choosing this option, stating, *'I am much more aware of what happens so, yes, I know that because I don't want my children to look after me, if I got to that stage. I would prefer to go into residential care'* (007: Black Welsh woman, aged 61).

Although the older people who took part in this study were aware of the fact that, at some point, more high level support may be needed, the thought of entering residential care was perceived by over half of them as something to be avoided. Many cited the lack of appropriate care they perceived they would get. Some participants expressed the view that, if they had to go into a residential care home, it would be one that was run by someone from their own community where, it was perceived, appropriate care would be provided. For others it was a possible indication that they had become too much of a burden for their families or that *'they [my family] dumped me in a Home because they have no time for me'* (004: West Indian woman, aged 71).

Lastly, for those respondents whose self-respect had, in some way, been linked to their physical independence, the loss of that independence was perceived as a significant threat to their personal and social identity. For instance, one participant's response to questions on how extra care and support would be secured was:

Well, I would ask my children first. Well, I probably wouldn't even have to ask them because you know they would see my situation you know. That would, I suppose, cut into my self-respect. Say for example right, I could no longer cook my own meals, I could no longer do my own washing, I would find that, even with my own children, it would diminish my sense of self-respect. Of course, if I had to have outside agencies, social services or something, what would happen to me?! Then it would be even worse again because as good as they are or as bad as they are from different reports you hear, you are having a total stranger in your home. You will have to rely on somebody right outside your own community probably nine times out of ten.

(017: Black Welsh man, aged 55)

Irrespective of how care was provided, some participants could foresee implications for their self-regard:

I suppose at the moment because I'm blessed with good health which is a biggie you know I can do things for myself and I am still able to move and go about the normal daily activities. But I think it's a big difference when you have to rely on people; for example, if somebody has to do something for you and where you have to rely on people and perhaps whoever is doing something for you doesn't make you feel valued and doesn't even listen to you, or show you any respect, it soon begin to play on your mind. I think that's when problems set in. So at the moment I'm able to maintain my self-respect because I can do all these things for myself and that makes it a lot easier. If circumstances were different then I don't know.

(009: African-Caribbean women, aged 56)

An element of retaining one's independence was being able to determine the level and extent of their care, explained by one participant as the need to "be kind and to do the things you cannot do for yourself in a moderate

way” (002: African-Caribbean woman, aged 73). This point was also made by another participant who explained:

If I have something to say or I have an opinion, it's respecting that opinion and respecting the things that I want. Like at the moment, I haven't been well. People have been generous and over generous with me but I can't always accept that so if I say no, leave it or I need to be doing it myself then people have to leave me to do the things myself.

(012: Black Welsh woman, aged 53)

Expectations of care

The participants had strong views on what constituted good quality care and in the way in which social care and services were delivered. The data revealed a number of pressing concerns and preoccupations. First, was the expectation that basic personal care was delivered in a manner that did not diminish a person's sense of self. Personal care that the participants were anxious to receive if needed, included toileting and changing soiled clothing and removing from rooms the causes of embarrassing smells from the room, the continuance established bathing routine, and being dressed appropriately. As one participant explained:

If I couldn't wash myself or whatever and this is what [the carer is] there for, then why should you suffer? They should try and help rather than just someone put a piece of food on the table and walk out. Just have a little word, a little chat, just to give the person confidence because people need confidence, especially when they're old and frail.

(001: Black West Indian woman, aged 80)

Another participant explained:

I think sometimes when you're providing care there's a difference between doing things that have to be done because you're caring for someone and you want them to have, and then there's a way in which you approach something which is about long-term care and about developing people's trust in you and stuff like that.... if it's a care thing

and it's about you having to have prolonged touching of people, and people are not happy with you because of certain things, then you have to have a different approach. I know certain people, I know [name of a relative] had certain rituals about washing, and I think you have to be respectful of how people have their own personal hygiene approaches... people do have different ways of washing.

(019: Black Welsh woman, aged 55)

Secondly, the participants also stressed that they wanted carers to show respect for their home, their possessions and their person but, above all, they wanted carers to treat them as they wished to be cared for themselves. As one participant explained:

I think my biggest bugbear from what I see and have experienced is individuals NOT putting themselves in the place of those for whom they're caring. I think if people do that, they wouldn't go far wrong. It is about having that empathetic feeling where you can put yourself in somebody else's shoes and, therefore, if you do that, if you're able to care for somebody in a way that you probably would care for yourself... if you did that, you wouldn't go far wrong. Because when you do that you would take into consideration all the different aspects: you'd want to have choice, you'd want to choose what you would like. It would just be reflection of what you would like for yourself.

(009: African-Caribbean woman, aged 56)

Thirdly, as with the above participant, the data revealed that what people were most keen to have acknowledged and respected was their individuality.

As one participant explained, *"You need to be treated as an individual because you can't do any of the other things unless you see that individual"*

(007: Black Welsh woman, aged 61). The view of another participant was:

It is so easy to think you are cloned... you all come from the Caribbean and you all behave a certain way and things like that. But each person is an individual and should be treated as an individual.... Yes, we are in a community, but I am an individual with my likes and dislikes...

(004: African - Caribbean woman, aged 71)

A fourth preoccupation was the attention to social markers linked to the personal and social identities of older people. For a very few, the concept of culture was not important, as one woman explained

I don't understand what people mean by culture because, you see, everybody is human and you should treat everybody equally. Why, I can't understand this culture business.

(002: African – Caribbean woman, aged 73)

For another participant who had been in the UK for over fifty years, her cultural preferences had developed and expanded:

I had to develop my culture here for so many years. I still like the food that they have at home but it doesn't bother me whether I get it yes or no. You have to adapt and adjust yourself to situation and circumstances for survival so culture you know...

(004: African-Caribbean woman, 71 yrs)

However, for the majority of those who took part in the study, an essential part of respecting a person's individuality was in exploring to what extent and in what manner these markers impacted on expectations of good quality care. Explanations cited in the interviews included:

Because then people are not stereotyping you, for example being a black person, people think we all eat, I don't know, rice and peas, we're all African Caribbean. No. If you want to know about me, I always say ask me and then you'll know about me. You can't lump me in with anybody else because we're all unique and we've all got our own ways. So it's being treated as an individual because if you're treated as an individual then you're treating me as me and you know me.

(012: Black Welsh woman, aged 53)

Because my culture is personal and comes from different points of view. Say I am a Sikh or whatever, there are variances... So being able to respect my individuality within that culture is quite important because otherwise again you might stereotype in a certain way... and expect me to react in a particular way.

(022: Black Welsh man, aged 62)

From the data it is evident that a key component in the delivery of quality care was the professional competencies of formal carers in being able to deliver person-centred care, or care that is rooted in the particular needs of the person. The professional competencies needed included but were not limited to acknowledging what a person considered to be important or having an awareness of possible, culturally-specific dimensions of a person's care. Rather, for many of the participants, professional competency was linked to actively valuing these differences so that any needs, preferences or requests arising from them were met. As one participant explained:

I think valuing culture is important. I think also to realise that cultures are different and people act differently in different cultures. So, yes, cultural awareness is a big thing and valuing that because people can be aware but don't value it enough to make an effort to ensure that that's taken into dignified care, yes.

(009: African-Caribbean woman, aged 56)

Also of importance was actively listening and communicating with older people – and their families – to ensure that the care and support delivered was in a professionally appropriate way. A number of components were cited, including one's tone and one's approach, as one participant explained, '*I think sometimes your mannerism, your approach to an individual, sometimes in the tone of your voice and speaking to people you can, you know, detect general deportment, you know. I think that plays a part*' (004: West Indian woman, aged 71). The role played by the family and the importance of communicating with family carers not in place of, but as part of, information-gathering work needed to provide appropriate care was also cited:

We knew the best way to approach my [name of relative] care but they weren't listening about that. They were more concerned with the rights of the patient if you see what I mean, which is divorced of the culture of the patient, the way in which the person wants to be touched and the food and all this sort of stuff and what they're going to eat.

(019: Black Welsh woman, aged 55)

Also important was listening and actively seeking out the views and expressed desires of older people. Linked to this is the fact that listening and communicating in the context of delivering care tailored to a person's specific needs is not difficult; rather it is something that we do in all areas of life. As one participant explained:

Participant: I think being heard and being treated as an individual are the key things in terms of dignity because what one person could review as respect and dignity, another person will not and so you can't assume...

(003: African-Caribbean woman, aged 53)

In reflecting on the perception that the subjective nature of dignity makes care more difficult, the participant's response was:

Participant: It doesn't make it harder...that's what you do all the time. You do it as part of communication. With every person you meet, you're adjusting and changing, so what's difficult or different? But sometimes as soon as it gets put on a table, it's defined.

Interviewer: Would it be something you would consciously do, do you think, or again is that contextual?

Participant: I think you do. I think if you view it as important then you do it all the time. I think if it's something that you don't view as important then you're less likely to pick up on the cues.

(003: African-Caribbean woman, aged 53)

For this participant, and for others, the delivery of professional care of quality was down to intentionality and focus – 'one's view' of the worth and importance of older people.

5

Summary of the main findings

INTRODUCTION

This chapter provides a summary of the main findings. The aim of this chapter is to identify some of the key factors that shape how the participants in this study understand dignity and to highlight what they consider to be significant markers of the provision of dignified care.



The study revealed that the concept of dignity is of practical concern and relevance to the older people who took part in this study. The concept of dignity was understood to be multidimensional and the term was often used alongside related terms such as 'respect' and 'pride'. The study also revealed that many of the components of dignity identified in the research literature remain relevant: dignity as stature, dignity as merit, and dignity as a basic human right (Jacelon et al. 2004, Nordenfelt 2004, Anderberg et al. 2007). Domains and indicators of dignity including autonomy, communication, end-of-life care, eating and nutrition, pain, personal hygiene, practical support/personal care, privacy and social inclusion also emerged as important to the participants (Picker Institute 2008).

Moreover, acknowledging, celebrating and respecting the virtue of age was, for many of the participants, deeply ingrained in their personal value system. Respect for older people was regarded by many as fundamental value for the participants. Specific ways of showing respect for older people and elders were revealed, as was the necessity of demonstrating this respect and of receiving respect in one's older age. In exploring the concept of dignity, it was also evident that being cared for in a way that acknowledges, respects and responds to an individual's personal, social and cultural identity has implications for their sense of dignity, self-respect and well-being.

The study revealed the almost unanimous view that mutual respect and reciprocity is vital to the fostering of dignity and the acknowledging of a person's self worth. It is this interpersonal dimension of dignity that can also lead to the diminishing or corroding of one's sense self-worth or self-dignity, a finding that resonates with the experiences of other older people in the UK (e.g., Calnan et al. 2006). This dimension of dignity has been developed by several authors including Jacelon (2003) who describes self-dignity as 'an attribute of dignity that is based on past accomplishments and is built over time, evidenced by an individual's behaviour and resilient in nature'. (p.547). The key messages repeated most often by the participants were: the universal right to be respected, the significance of one's self-worth, the links

between self-respect and dignity in social encounters, and the impact of the social positioning of older age and societal discrimination.

In exploring personal identity, it is evident that dignity has a structural dimension, as well as an interpersonal dimension, both of which are constructed by the act of recognition. The study revealed that, as aspects of personal identity, social markers such as ethnicity and cultural identity do play a role in shaping one's understanding of the concept of dignity and how they felt they were perceived and 'recognised' by others in their everyday lives. Of equal importance to this study is social identity, as linked to group and intergroup relations.

The study showed that the process of racialisation can impact, to varying extents, on the participants' daily lives. Just as racialised differentials in health are increasingly being understood not simply as the result of 'cultural differences' but rather within the context of wider social, historical, economic and political factors (Anderson et al. 1989; Ville et al. 1994; Higginbottom 2006), so too must social care access, acceptance, uptake and avoidance. It is not solely about changing attitudes; it is about tackling wider structural barriers – barriers that are as much about age as they are about other social markers such as the race concept and ethnicity. It is equally important to seek to understand that affiliation to a community group, in this case a racialised community group (that is, it must be noted, as fluid and ever-changing as other groupings) can bring material, practical and symbolic resources and can foster strategies and interventions that, in turn, are played out in individual interactions with others in care settings and care-seeking encounters.

The notion of what constitutes 'care' may be interpreted differently between and within different ethnic groups (PRIAE 2008). The study revealed the informality some participants attached to some forms of 'formal' care. Also of importance was the inverting of the common view that

respect is an important part of dignified care. For many of the participants, care was an important dimension of respect. Moreover, the study revealed that, even allowing for differential understandings as regards the definition of care and support, the uptake and use of statutory support services amongst the participants was low. Some participants had limited knowledge about the type of practical and financial support available to them, with there being a stark separation between low level support and high level support. Access to services was an issue for some, especially with the first point of contact for many agencies now being via automated telephone services or online. The study also highlighted the fact that many of the participants who were even aware of the range of social service provision available to them still did not consider seeking such support for themselves. There was a sense that people were reluctant to ask for help either informally or formally. Many of the participants, although not all, expressed a dogged determination to carry on without external intervention.

There is evidence that the proportion of elderly minority ethnic people living in UK care homes is far less than the rest of the population (Banks et al. 2006). Although it is suggested that this is, in part, due to the desire to retain independence and to receive support and care from family members, friends and neighbours, access, acceptability and appropriateness of prevalent supports and services were also important considerations. If residential care had to be considered, many but not all participants expressed a preference to be in a home run by people 'from their community'.

In the main, the participants expressed a preference for being looked after by family members, though, equally, most wished to remain independent for as long as possible. Thus, the role of the family in providing care, the way in which 'formal' care was conceptualised and came to be understood by some as 'informal' and incidental, the importance for some of the participants to 'soldier on' and to avoid asking for help, coupled with the lack of knowledge,

for some, of the medium level supports offered are all key factors in shaping the participants' understanding, uptake or avoidance of social care provision. As noted above, this was not the case for all the participants; some indicated in their responses that they would actively seek, and indeed would prefer, formal social care provision.

Lastly, the study revealed that older people have strong views on what constituted care and what they considered to be indicators of care with dignity. These included: acknowledgment of and attention to social markers linked to the personal and social identities of older people, as articulated by the person ('dignity with no assumptions'); professional competency of carers: active listening and communication; care that prolonged autonomy and independence; care delivered by people who were not only aware of individual preferences and cultural differences (or similarities as the case may be), but who were responsive and made appropriate adjustments. These were considered key enhancers and indicators of dignified care.

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